



# Partnerships for a Positive Future



2009 Study Results from the Workgroup  
on the Future for People with  
Severe Developmental Disabilities,  
including Autism





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## Message from the County Executive



As County Executive, I recognize the rich and vibrant contribution each member of our community makes to the total diverse fabric of Montgomery County. In order to preserve and enhance this wonderful gift of our diversity, we must strive to ensure that every resident has access to all services and to the recreational, educational, arts, leisure and community activities in which they wish to participate.

It is with great pride that I introduce a publication that will play an important role in shaping the County's response to the needs of children and adults with severe developmental disabilities. The Report on People with Severe Developmental Disabilities, including Autism is the result of a visionary and collaborative process involving parents, advocates, and representatives from the public and private disability service systems. Through an extensive outreach, data collection and assessment process, we now have a more comprehensive understanding of the needs of the severely developmentally disabled population and the URGENCY to respond to those still waiting for services.

I thank the many people who participated in this process, from those families who willingly participated in the focus groups to those individuals that researched services and data across the country. Because of your efforts, a tangible difference will be made in the lives of many of these individuals who call Montgomery County home.

Isiah Leggett  
Montgomery County Executive



## Message from the Director of the Department of Health and Human Services



Early in 2008, a group of 18 committed family members, government officials, representatives from the private sector and advocates came together to discuss the unmet needs of the growing number of people with severe developmental disabilities. According to the U.S. Administration on Developmental Disabilities, approximately 4.5 million individuals with developmental disabilities live in the United States. We have learned that developmental disabilities affect approximately 17% of children aged 18 years or younger. These statistics, along with the data documenting over 2,600 individuals on the State waiting list for services, bring home the urgency of our need to develop effective strategies to address the problem.

We are aware that various barriers exist and that children remain on the Autism Waiver waiting list between 4-6 years while adults wait for 5-15 years on the state waiting list. We are sensitive to the fact that families carry an enormous responsibility in caring for their family member(s). This report helps define the scope of the problem and guides us through relevant action steps that can be taken by policy-makers, provider agencies, advocates and families/consumers. A tremendous amount of outreach and research went into the development of the report.

I want to thank each of the members of the Workgroup and the families who so willingly shared their stories and recommendations. We believe this will be an important building block in our County's efforts to address the needs of individuals with developmental disabilities. I encourage you to join us as we continue to work on this very important issue affecting the lives of numerous Montgomery County families.

Uma S. Ahluwalia  
Director

# Message from the Co-Chairs



## A MESSAGE FROM THE CO-CHAIRS OF THE MONTGOMERY COUNTY WORKGROUP ON THE FUTURE FOR PEOPLE WITH SEVERE DEVELOPMENTAL DISABILITIES, INCLUDING AUTISM:

People with severe developmental disabilities of all ages are in crisis. Their needs are intense, continuous, unrelenting, and life-long. We see it every day in our interactions in the community, in requests for assistance made to Montgomery County Government, in collaborations with schools and service providers, and in our day-to-day encounters with families. This two-part report highlights the ***Need for Urgency*** in addressing the needs of people with severe developmental disabilities and their families, and presents a ***Call to Action***, with priorities and recommendations—most of which can be accomplished with little or no cost.

Our thanks to the committed family members, advocates, service providers and County government staff who contributed their time, creativity and expertise in creating this report. **Now** is the time to act — to join forces to support this Call to Action and address the critical unmet needs of people of all ages with severe developmental disabilities and their families.

Lyda Astrove and John J. Kenney, Workgroup Co-Chairs

# Addressing a Crisis: The Need for Urgency



Montgomery County residents with severe developmental disabilities, including autism, often languish for years on waiting lists, on average from 5-15 years. Many come from families in crisis; and many have elderly caregivers, some of whom are disabled themselves.

Early in 2008, a group of family members, Montgomery County officials, and private service providers came together to discuss ways to address the unmet needs of increasing numbers of people with severe developmental disabilities. Because of the crisis situations in which families and service providers often find themselves, the workgroup sought to develop proposals and action plans that would increase the capacity of the service system to support people with intensive needs, and provide support to their families and the professionals with whom they work.



*“There are unlimited possibilities  
when people are creative and expect  
the best.”*

## The Workgroup



Co-Chairpersons Lyda Astrove and Dr. John J. Kenney convened the Workgroup on Severe Developmental Disabilities, including Autism. The 18- member workgroup included parents, advocates, and representatives from public and private disability services. The workgroup’s charge was to determine the extent of the need, define the people most in need of intensive support, and decide which needs should have highest priority. Workgroup members sought input from families throughout the county, examined current policy and legislative barriers, and researched best practices in services and support for people of all ages with severe developmental disabilities.

# Findings: What We Learned



In reviewing data from a County-wide survey and focus groups, two overarching and interrelated issues were expressed repeatedly by families, people with disabilities, and service providers.

- 1 There is a need for urgency! We collectively must respond with urgency in addressing the ongoing needs of children and adults with severe developmental disabilities.**
- 2 We must have higher expectations for people with severe developmental disabilities—regardless of an individual’s diagnosis.**

From childhood years onward, a lack of urgency in providing individualized services and the absence of high expectations translate into wasted days and years—resulting in dependent, unproductive lives. We get what we expect. If we believe that a person with developmental disabilities will never hold a job or gain independence, there is little motivation to provide a high-quality education, career counseling or job training. Stereotypes abound about people with the most severe disabilities, most of which serve to limit the opportunities made available to them.

We also heard and learned that people with severe developmental disabilities have very few service options, are socially isolated, have little to no support for becoming contributing members of society, and largely do not participate in the life of their communities.

## Who are People with Severe Developmental Disabilities, including Autism?



People with severe developmental disabilities have lifelong disabilities and require continuous support from family members, formal service providers, and other support networks. Severe developmental disabilities create barriers in three or more life areas, —including someone’s capacity for independent living, economic self-sufficiency, learning, mobility, comprehensive and language skills, self-care, self-direction, or the ability to function independently without individually planned and coordinated services. Therefore, people require intensive and continuous long-term support. It is difficult to determine the prevalence of people with severe developmental disabilities because of inconsistent classification and tracking systems.



# What is Life Like for People with Severe Developmental Disabilities and their Families?

In the December 2008 journal *Pediatrics*, researchers published the results of a national survey on the impact on families of raising children with special health care needs. Data indicates that parents of children with autism are *three times more likely* to quit their jobs or reduce work hours to care for their children compared to parents whose children have other chronic health care needs. The study showed that the support needs of children with autism place an enormous financial strain on families. In addition to lost income, families pay more for their children's health and support needs, and spend more time providing or arranging for their care.

There is enormous evidence that, with early intervention, challenging educational experiences and the availability of flexible individualized services and support, people with disabilities are most limited not by their disabilities but *by our expectations of them*. It is only in the last decade that we are not surprised to hear of children with Down Syndrome reading at grade level, or adults with autism attending college, writing books, and working as motivational speakers.

However, their unmet needs are staggering. While the number of people diagnosed with severe developmental disabilities increases, needs for services and supports fall further and further behind and the pool of available service providers continue to shrink.

## **Families caring for children and adults with severe developmental disabilities worry.** They worry:

- About the future.
- That they're not doing enough, even though they are exhausting themselves with their efforts.
- That their son or daughter will never get off the waiting list.
- That they are neglecting their other children, their marriage and their health because of the intense demands of caregiving.
- That their son or daughter will always be vulnerable, and they won't be there forever to protect them.
- That they will never get out of debt from out-of-pocket expenses they incur to fill in service gaps.
- That there are too few high-quality service providers from which to choose.
- That their son or daughter will remain socially isolated and friendless.
- That their son's or daughter's life is being wasted due to missed opportunities and low expectations.

## DID YOU KNOW...

- ⦿ As of July 2008, 18,024 people were on the waiting list for services from the Developmental Disabilities Administration (DDA). Of these, 94% need services immediately. Many are living with elderly caregivers or are young families with no support. The waiting list grew by 774 in the six months between January and July 2008 (Developmental Disabilities Coalition, 2008).
- ⦿ Although Maryland is the wealthiest state in the nation and has the lowest poverty rate of any state, Maryland ranks 44th in its spending on developmental disabilities services (The Arc of Maryland, 2008 Public Policy Platform).
- ⦿ According to Cornell University's Disability Status Report for Maryland (2008), the employment rate for working age people with disabilities was 42.8%. Only 25.9% reported that they worked full-time for the full year. The poverty rate for working-age people with disabilities is 20.1%, compared to 5.5% for people without disabilities.

# Guiding Principles



The following guidelines and principles should be applied to proposed solutions, recommendations, and their resulting outcomes.

**Nothing about us without us.** Planners and service providers should actively solicit input from people with disabilities and their families, and ensure that they have an *ongoing* means for communicating and offering input.

**Coordinate services across settings.** Support and services need to be systematically coordinated across settings and transitions, with special attention to clear and collaborative communication.

**Ensure easy access to information and assistance.** Information, transition support, family support, formal and informal services, training opportunities—all these should be easily accessible, well-publicized, and effectively promoted to people with disabilities, their families, and their staff.

**Set high standards and provide support for continuous learning through professional development and training.** Providers working with people with severe developmental disabilities should have consistent support to develop core competencies and build their expertise through training, mentoring, and higher education.

**Provide updated information on best practices.** Professionals, family members, and people in the community should have access to current best practices for supporting, working with, and successfully including people with severe developmental disabilities in a variety of settings.

**Support and attract providers.** Support current community service providers and attract new high-quality providers to deliver direct support and/or medical and therapeutic services



*“It’s very hard to find your way through the alphabet soup of service while still trying to give your child and your family what they need on a day-to-day basis.”*

# Priorities

The workgroup identified five critical priorities.

## **PRIORITY 1. Respond proactively to people in crisis who are on waiting lists, and advocate for more services and options.**

This is an urgent need for several reasons. The increasing number of people on already long waiting lists puts a significant strain on limited resources. Also, many families have expressed dissatisfaction with the quality of services, both for children and adults, including the inability of many providers to individualize support for their family member.

In July 2008, there were 2,842 Montgomery County residents on the Maryland Developmental Disabilities Administration's (DDA) waiting list, which represents a significant percentage of the 18,024 people on the waiting list statewide (see [www.endthewaitnow.com](http://www.endthewaitnow.com)). In October 2008, there were 2,351 children state-wide on the waiting list for autism waiver services, of which 481 were from Montgomery County. Statewide, the Autism Waiver Program has only 900 available slots and is capped at this number.

There also is a lack of collaboration and coordination between agencies and departments, resulting in wasted time, duplication of efforts, and missed or delayed outcomes.

*“DDA approved my son’s funding but none of the agencies accepted his application. Now DDA took back his funding and he is once again on the waiting list.”*

## **PRIORITY 2. Provide support for people through service and life cycle transitions, while ensuring that they move into activities and services that are meaningful and that enable them to learn, grow and contribute.**

Many Montgomery County families noted that they encountered a lack of responsiveness in trying to access services or information, which leads to delays or failures in receiving support for their family member. Consequently, many families reported being unprepared for upcoming transitions—lacking adequate



## DID YOU KNOW...

- 2002 U.S. Census Bureau data reports that 32.5 million people (12% of the general population) have a severe disability.
- Developmental disabilities affect approximately 17% of children aged 18 years or younger, resulting in substantial financial and social costs (CDC, Monitoring Developmental Disabilities, 2006).
- Statewide, the Autism Waiver Program has 900 available slots and is capped at this number. In October 2008, there were 2,351 children state-wide on the waiting list. The current wait time for a child added to the Autism Waiver waiting list is now 4-6 years.
- The Infants and Toddlers Programs received 2,255 new referrals in FY 2008 and provided service to 3,632 children and their families, which is an increase from the 1,995 new referrals in FY 2007 and service provided to 3,484.

information to make timely, informed decisions; sufficient lead time; and support in planning and working through the details of the transition.

If people envision a positive future for children and adults with severe developmental disabilities, they are more likely to provide meaningful opportunities and encouragement for growth. Setting high expectations for people with severe developmental disabilities is critical, and is a recurring theme expressed by Montgomery County parents. Their fears and concerns are reflected in national unemployment data as well. People of employment age (21-64) who reported having a severe disability have the lowest rate of employment compared to people with non-severe disabilities or no disabilities at all (US Census Bureau, 2007). In a recent national survey (Easter Seals, 2008), 79% of parents of children with autism were extremely or very concerned about their child's future independence, compared to 28% of parents of children without autism.



*“I wish there was a one-stop shop where I could be advised on what options and benefits there are for my daughter as she moves into adulthood.”*

### **PRIORITY 3. Increase support to families across the lifespan.**

Families are the largest single group of caregivers for people with disabilities—providing a greater quantity and, in many instances, quality of care, especially to people with severe developmental disabilities. In providing this support, care, guidance and education to their family members, they save the county and state millions of dollars. Even when families receive in-home support, personal assistance and community living support, they still provide oversight, quality control, ongoing training for staff, and service coordination. In some instances, depending on the service and funding source, families also recruit, train and supervise staff. For all of these reasons, it is in the best interest of Montgomery County and the State of Maryland to preserve, strengthen and support families.

Families with a family member with a severe disability experience significant stress due to the relentless demands on their time (intensive daily caregiving, medical and therapeutic appointments, coordinating care and services, and advocating on behalf of their family member). Because of this, most families experience social isolation, marital difficulties, and strain on all family members, including siblings.

Many Montgomery County families noted difficulties in accessing services or information. Without clear access to information, they did not know their options and could not adequately prepare for

upcoming changes. They wasted precious time making dozens of calls and visits before getting the information they needed.

In the Workgroup's survey, only 24% of families reported using respite care services in the past year—a service that provides a much needed break from the ongoing demands of caregiving. When asked why they didn't use this service, 41% of respondents indicated an inability to find a caregiver or to afford the service. Only 32% of respondents indicated that they did not need the service. These responses were unrelated to the age of the family member. Families, including those on waiting lists, would benefit from the flexible support provided by respite services if the current barriers could be removed. Barriers include limited respite models; inadequately trained staff; difficulty finding staff for in-home and community support (in part due to inadequate compensation); and the physical inaccessibility of the County's respite house.

Having a family member with a severe developmental disability imposes economic hardships on the family, as highlighted in the previously mentioned December 2008 study published in *Pediatrics*. In the workgroup's survey, 61% of respondents reported that providing care to their family member has caused them either to leave their job (26%) or reduce their hours (35%). Of the 145 parents who responded to a question about their total out-of-pocket monthly expenditure for behavioral or therapeutic services, they collectively reported paying for over 400 services a month, totaling almost \$140,000 monthly. This may not include other direct support, medical and dental services, which are not covered by insurance or other funding sources. Many too have to travel to find doctors and dentists who have experience working with people with severe developmental disabilities.

Most adults with severe developmental disabilities are unemployed and, therefore, require support during the workday. This makes full-time employment impossible for many families. Also, many day programs operate only 5-6 hours per day, which also makes full-time employment difficult for families, given that people with severe developmental disabilities require ongoing support and supervision.

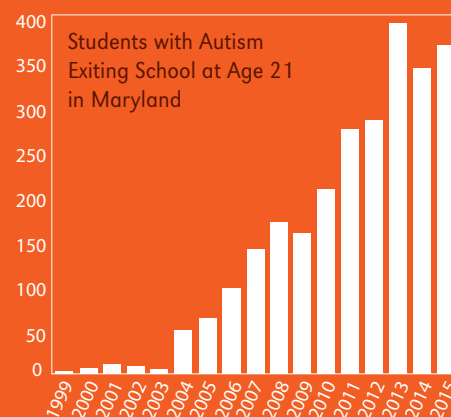
In a 2008 study by Easter Seals, 74% of parents of children with autism fear their children will not have sufficient financial support after they die, while only 18% of typical parents share this fear. The study also highlighted that parents are extremely or very concerned about their family member's future independence (79%), quality of life (77%), employment (77%), housing needs (69%) and education (73%)—all in stark contrast to the concerns expressed by parents of children without autism.



## DID YOU KNOW...

- ⦿ The number of students with disabilities who exit school in Montgomery County annual has ranged from 83-101. Statewide, the number of students with autism who leave school continues to rise (see Figure 1).
- ⦿ This year, there were 16,485 students receiving special education services, of which 1,197 were preschoolers diagnosed with a developmental delay and 2,177 were students categorized as having a severe developmental disability. This number also included 1,308 students diagnosed with autism.

Figure 1: Students with Autism Becoming Adults



Source: Maryland State Department of Education census date 1999- 2003



*“We paid over \$40,000 out of pocket in 2007 for our child with PDD-NOS, a mild form of autism. It is crippling us financially.”*

**PRIORITY 4. Increase the number of highly-skilled, responsive, and adequately paid people to provide direct support, medical, dental and therapeutic services.**

There is an extremely high turnover rate among direct support staff who work with children and adults with severe developmental disabilities. This directly affects the quality of service people receive. Also, there is an insufficient number of providers of medical, dental and therapeutic services who have expertise working with children and adults with developmental disabilities and/or who accept Medicaid. Even providers who are experienced in working with people with severe disabilities often limit their services because of the substantial time commitment and inadequate reimbursement. Therefore, there is a need to create incentives for people to pursue and remain in careers in which they specialize in severe disability. In addition, because families often have to travel long distances to find services, it is critical that we support the development of local expertise.



*“No one can fully understand the cost and work of raising a disabled child unless in that situation. Speech therapy costs \$185 per visit. Floor time costs \$295 per visit. Parents must do the therapy with the child between visits, and often it’s a choice between therapy or going to work.”*



## **PRIORITY 5. Identify and utilize the full array of community services and supports available to all County residents.**

People with developmental disabilities, especially severe disabilities, live fuller and more productive lives when they are engaged with all that their communities have to offer. It is unrealistic and undesirable to propose that the formal government-funded service system fully meet all of an individual's needs. People require broad and diverse support networks that will open doors to opportunities and keep them safe and healthy. Utilizing these community supports and services is cost-efficient, since the support that people receive from neighbors, community members, members of faith communities, and co-workers is freely given. The lifetime costs for a person with autism (including education, home and community-based services, and lost individual and family income) are estimated to be \$3.2 million (Ganz, 2007)—a number likely to be similar for people with other severe developmental disabilities. These extreme costs can be mitigated by both early intervention and the use of informal and/or typical community services.



*“I’m worried about  
my son’s future.”*

For recommendations, see **A CALL TO ACTION: STRATEGIC STEPS FOR REAL CHANGE**, which details immediate steps that can be taken, most at little to no cost, as well as short and long-term activities to address the critical issues facing people with severe developmental disabilities and their families. This companion document is available at <http://www.montgomerycountymd.gov/hhstmpl.asp?url=/content/hhs/ads/disabilitysite.asp>.

*For more information about these reports, please contact :*  
*Montgomery County Department of Health and Human Services*  
*Aging and Disability Services*  
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# Definitions



**Autism Spectrum Disorders (ASDs).** This group of developmental disabilities is defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. The thinking and learning abilities of people with ASDs can vary—from gifted to severely challenged. ASD begins before the age of three and lasts throughout a person’s life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in males than females. (Centers for Disease Control and Prevention (CDC): Autism Information Center, <http://www.cdc.gov/ncbddd/autism/index.htm>).

**Developmental Disability.** This term (as defined by the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402) refers to a severe, chronic disability of an individual that:

1. Is attributable to a mental or physical impairment or combination thereof.
2. Is manifested before the individual attains the age of 22.
3. Is likely to continue indefinitely.
4. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency.
5. Reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized support, or other forms of assistance that are of lifelong or of extended duration and are individually planned and coordinated.

**Family Support.** This term refers to resources, subsidies, services, and other assistance provided to families of persons with disabilities that are designed to support families in their efforts to maintain family members with disabilities at home, strengthen the role of the family as primary caregiver, prevent inappropriate and unwanted out-of-home placement, maintain family unity, and connect families with persons with disabilities who have been placed out of the home, whenever possible. The term includes service coordination, goods, services and financial assistance.

**Intellectual Disability.** This is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18 (American Association for Intellectual and Developmental Disabilities). Intellectual disability is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability has historically also been referred to as a cognitive disability or mental retardation (Centers for Disease Control and Prevention (CDC): National Center on Birth Defects and Developmental Disabilities, <http://www.cdc.gov/ncbddd/dd/ddmr.htm>, 2005).

**Severe Developmental Disability.** There is not a single definition for severe developmental disability, as definitions tend to be specific to what a person’s unique disability may limit. For the purposes of this report, a severe developmental disability is one that creates significant barriers to one or more of an individual’s abilities (such as mobility, learning, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) so that the individual requires intensive and continuous long-term support.



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# Workgroup Members



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## **Montgomery County Department of Health and Human Services**

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